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Healthcare Expenditure Burden Among Non-elderly Cancer Survivors, 2008–2012

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Abstract

Introduction: There is increasing concern regarding the financial burden of cancer on patients and their families. This study presents nationally representative estimates of annual out-of-pocket (OOP) burden among non-elderly cancer survivors and assesses the association between high OOP burden and access to care and preventive service utilization.

Methods: Using the 2008–2012 Medical Expenditure Panel Survey, 4,271 cancer survivors and 96,780 individuals without a history of cancer were identified, all aged 18–64 years. High annual OOP burden was defined as spending > 20% of annual family income on OOP healthcare costs. Associations between high OOP burden and access to care were evaluated with multivariable logistic regression. Analyses were conducted in 2015.

Results: Compared with individuals without a cancer history, cancer survivors were more likely to report a high OOP burden (4.3% vs 3.4%, p=0.009) in adjusted analyses. High OOP burden was more common among cancer survivors who were poor (18.4%), with either public insurance (7.9%) or uninsured (5.7%), and not working (10.2%). Among cancer survivors, high OOP burden was associated with being unable to obtain necessary medical care (19.2% vs 12.5%, p=0.002), delaying necessary medical care (21.6% vs 13.8%, p=0.002), and lower breast cancer screening rates among age-appropriate women (63.2% vs 75.9%, p=0.02).

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Conclusions: High OOP burden is more common among adults with a cancer history than those without a cancer history. High OOP burden was associated with being unable to obtain necessary medical care, delaying necessary medical care, and lower breast cancer screening rates among women.

Introduction

An estimated 14.5 million Americans with a history of cancer were alive in 2014.[1] Previous research has shown that cancer survivors face greater healthcare expenditures including out-of-pocket (OOP) costs compared with individuals without a history of cancer.[2–5] High OOP costs can reduce access to care, influence clinical practice, and affect treatment choices.[6,7] By creating a financial barrier, OOP payments can lead to reduced use of preventive services and uptake of preventive medications.[6,8] For example, higher OOP costs are associated with lower rates of screening for breast cancer, cervical cancer, and colorectal cancer among certain populations.[8–10] Reduced access to care among cancer survivors may affect surveillance and treatment for disease recurrence, screening for additional cancers, and care for the late and lasting effects of cancer treatment.[11,12]

Limited information exists on OOP burden among cancer survivors at the national level. Previous studies have addressed OOP burden among cancer survivors by treatment status, rather than among all cancer survivors together,[5,13] or have focused on cancer patients aged ≥ 65 years.[13] Additionally, few studies have evaluated the association between OOP burden and access to care and preventive service utilization among cancer survivors. This study provides a comprehensive analysis of OOP burden among non-elderly adult cancer survivors aged 18–64 years. Using nationally representative data, this study examines the prevalence of high annual OOP burden and the association between high annual OOP burden and access to care and preventive service utilization among non-elderly cancer survivors.

Methods

Data Sources

The study sample was selected from the 2008–2012 Medical Expenditure Panel Survey (MEPS) Household Component. The MEPS is a nationally representative sample of the U.S. civilian non-institutionalized population that collects detailed information on demographic characteristics, health status, income, health insurance, employment, access to care, and healthcare expenditures (including OOP expenditures). In-person interviews are conducted with an individual who responds for all members of the household. The annual response rate ranged from 53.5% to 59.3% during the study years included in the analysis. More-detailed information on the MEPS survey design and content is available elsewhere.[14,15]

Cancer survivors were defined as any person who has ever been diagnosed with cancer. Using the 2008–2012 MEPS, 4,271 cancer survivors aged 18–64 years were identified based on the question: *Has a doctor or other health provider ever told you that you have a cancer or malignancy of any kind?* The comparison group consisted of the remaining 96,780 adults in the same age range who did not report a history of cancer. Similar to previous studies,

individuals diagnosed solely with non-melanoma skin cancer were not classified as cancer survivors.[2,16]

Measures

Sociodemographic characteristics of cancer survivors at the time of the survey included: time since diagnosis, age, sex, race/ethnicity, educational attainment, marital status, number of comorbid conditions, health status, health insurance status, employment status, and family income as a percentage of the federal poverty level (FPL). Poor people were defined as having family income < 100% FPL, near-poor and low-income people were defined as having income 100%–200% FPL, and middle- and high-income people were defined as having incomes ≥ 200% of FPL. The number of comorbid conditions was determined through a series of questions about whether a doctor or other healthcare professional ever told the person that they had any MEPS priority condition, including arthritis, asthma, diabetes, emphysema, heart disease, hypertension, stroke, and high cholesterol.

Annual OOP burden was measured as the percentage of OOP costs relative to family income. Annual OOP burden included OOP expenditures toward any healthcare service, such as coinsurance, copayments, and deductibles. Expenditures include those for cancer screening, surveillance, and treatment, as well as medical care for other health conditions. Consistent with previous research, OOP burden was defined at the family level, as families typically share financial resources.[5] Family-level burdens were assigned to individuals within the family, allowing the analysis to be conducted at the individual level. Similar to previous studies, high OOP burden was defined as having annual OOP spending > 20% of annual income.[5,17] For families reporting very low or negative incomes (1.8% of cancer survivors in the sample), a $100 floor for family income was imposed.[5] The results were not sensitive to the adjustment.

Several access to care measures were evaluated based on both the availability of care and actual utilization of healthcare services in the past year. Access to care measures included:

- having a usual source of care;
- having difficulty getting to a usual source of care;
- being unable to get necessary medical care, dental care, or prescription medications; and
- delaying necessary medical care, dental care, or use of prescription medications.

Preventive care was evaluated by examining preventive service use and cancer screening services recommended by the U.S. Preventive Services Task Force[18] and vaccinations recommended by the Advisory Committee on Immunization Practices[19] and potentially covered by provisions of the Affordable Care Act (ACA). Preventive services included:

- blood pressure screening within the past 2 years;
- cholesterol screening within the past 2 years;
- influenza vaccination in the past year; and

- breast, cervical, and colorectal cancer screening within recommended screening guidelines.

Cancer screening was assessed among age- and gender-eligible men and women. Receipt of mammography within the past 2 years among women aged ≥ 40 years was used to identify women up to date with breast cancer screening guidelines. Receipt of the Pap test within the past 3 years among women aged 21–64 years who had not had their cervix removed was used to identify women up to date with cervical cancer screening guidelines. Adherence to colorectal cancer screening guidelines was assessed by examining the receipt of a fecal occult blood test within 1 year, sigmoidoscopy within the last 5 years, or colonoscopy within the last 10 years among men and women aged 50–64 years to identify individuals up to date with screening. Individuals with a history of the specific cancer in each analysis were excluded to ensure that preventive screenings were captured rather than surveillance.[20]

Statistical Analysis

Descriptive statistics were calculated for cancer survivors and individuals without a history of cancer and compared using chi-square statistics. Multivariable logistic regression models controlling for age, sex, race/ethnicity, marital status, education, and number of comorbidities were used to compare annual OOP burden among cancer survivors and individuals without a history of cancer. Overall results and results stratified by demographic factors as well as family income, health insurance, and employment status are presented. The adjusted percentages of adults with a high OOP burden are presented as predictive margins, which standardize the outcome of each group to the covariate distribution of the population.[21]

Multivariable logistic regression models were used to assess the relationship between high OOP burden and access to care and preventive service utilization among cancer survivors. Predictive margins were generated to compare these measures among cancer survivors by OOP burden status controlling for age, sex, race/ethnicity, marital status, education, and number of comorbidities.

Person-level weights were applied to account for the complex study design of the MEPS and reflected probability of selection, adjustments for non-response, and post-stratification to provide nationally representative estimates. All analyses were conducted using Stata, version 14.0. Analyses were conducted in 2015.

Results

Cancer survivors were more likely to be older, female, non-Hispanic white, have more comorbid conditions, report being in fair or poor health, insured, more likely to be married, and more likely not to be working than individuals without a history of cancer (Table 1). More than a third of cancer survivors (36.7%) were diagnosed within the past 4 years, and 39.1% were diagnosed at least 10 years before the survey.

Cancer survivors were more likely to have a high annual OOP burden compared with those without a history of cancer. After adjusting for other covariates, 4.3% of cancer survivors had a high OOP burden compared with 3.4% of individuals without a history of cancer

(p=0.009, Table 2). Among individuals aged 50–64 years, cancer survivors were more likely to report a high total OOP burden than individuals without a history of cancer (p=0.02), whereas similar rates of high OOP burden were found among those aged 18–49 years regardless of their cancer history. Near-poor and low-income along with middle- and high-income cancer survivors were more likely to have a high annual OOP burden compared with individuals in the same poverty level categories but without a history of cancer (p=0.02 and p=0.003, respectively). High OOP burden was more common among privately insured cancer survivors than among privately insured individuals without a history of cancer ($p < 0.001$). High OOP burden was more common among cancer survivors working full-time than among individuals without a history of cancer working full-time (p=0.02).

Among cancer survivors, the prevalence of high annual OOP burden varied across a number of sociodemographic characteristics. High OOP burden was more common among the poor (18.4%) and the near-poor and low-income (4.6%), compared with those with middle and high incomes (1.0%). Among cancer survivors, high OOP burden was more common among those with public insurance (7.9%) and the uninsured (5.7%) compared with cancer survivors with private health insurance (3.2%). High OOP burden was more common among cancer survivors who were not working (10.2%) compared with those working part-time (4.2%) and those working full-time (1.7%).

Cancer survivors with a high annual OOP burden were more likely to report that they were unable to obtain necessary medical care, dental care, or prescription medications (19.2% vs 12.5%, p=0.002) and delayed necessary care (21.6% vs 13.8%, p=0.002) compared with cancer survivors without a high OOP burden (Table 3). Among female cancer survivors, breast cancer screening rates were lower among those with a high OOP burden compared with those without a high OOP burden (63.2% vs 75.9%, p=0.02).

Discussion

This study demonstrates that cancer survivors are more likely to report a high annual OOP burden than individuals without a history of cancer. High annual OOP burden is more common among poor cancer survivors, those with public insurance or the uninsured, and those not working. Among cancer survivors, high OOP burden is associated with being unable to obtain necessary medical care and delaying necessary medical care. Additionally, high OOP burden is associated with lower breast cancer screening among age-appropriate female cancer survivors.

Although there is literature underscoring the financial burden of cancer survivorship, this is the first study to quantify the prevalence of high annual OOP burden and its association with access to health care and preventive service utilization among non-elderly cancer survivors at the national level. These findings support previous research among cancer survivors highlighting the association between higher cost sharing requirements and forgoing or delaying medical care.[22,23] Access to care is particularly important for cancer survivors, given their increased risk of developing other chronic conditions, and long-term adverse health effects, including cardiotoxicity, lymphedema, sexual dysfunction, incontinence, pain, fatigue, cognitive dysfunction, and psychological distress.[24,25] Cancer survivors also have an

increased risk of secondary cancers.[26,27] Previous studies have highlighted disparities in access to care among cancer survivors and the importance of ongoing efforts to improve access to care among this population.[20]

The findings suggest that non-elderly female cancer survivors who reported a high annual OOP burden were less likely to report having a recent mammogram. Access to recommended preventive care such as breast cancer screening is critical for cancer survivors, as they are at an increased risk of developing other cancers and may experience late and lasting effects of cancer treatment.[25–27] The ACA provides many opportunities for prevention. Millions of Americans are now eligible for health insurance coverage through the Health Insurance Marketplace and Medicaid expansion in most states, giving them better access to health services, including preventive services. The ACA requires non-grandfathered private health plans and newly eligible beneficiaries of the Medicaid expansion to provide coverage without cost sharing for preventive services rated as “A” (strongly recommended) or “B” (recommended) by the U.S. Preventive Services Task Force, for vaccinations recommended by the Advisory Committee on Immunization Practices, and services for infants, women, and children recognized by the Health Resources and Services Administration.[28] By requiring many plans to cover recommended clinical preventive services with no cost sharing to the patient, including screening for breast, cervical, and colorectal cancer, the ACA can help reduce financial barriers to the receipt of recommended preventive care. However, it is not clear if these changes alone will increase access to care among cancer survivors faced with high annual OOP burden. Other barriers such as lack of paid sick leave may inhibit the receipt of recommended preventive services.[29] Ongoing evaluation of access to recommended preventive care will be important as the ACA continues to be implemented.[30]

The current study found that high annual OOP burden is associated with higher rates of delaying or forgoing needed medical care among cancer survivors. Delaying or forgoing needed medical care among cancer survivors may negatively affect surveillance for disease recurrence and care for the late and lasting effects of cancer treatment.[11,12] Higher OOP costs have also been shown to reduce adherence to cancer treatment.[23,31] In a survey of medical oncologists, 84% reported that patient OOP spending influenced treatment recommendations,[7] with 16% acknowledging that they omitted treatment options on the basis of their perceptions of patients’ ability to afford treatment.[32] The American Society of Clinical Oncology Value in Cancer Care Task Force has emphasized the important role of patient and provider communication on issues surrounding cost.[33] However, many physicians may be uncomfortable discussing costs with patients.[32] The negative impact on the health of cancer patients because of high OOP costs and the financial burden associated with treatment related to cancer has been characterized by Ubel and colleagues[34] as “financial toxicity.” As these authors have explained, providers frequently discuss toxicities of treatment, but these discussions typically refer to the physical side effects of treatment. Meanwhile, financial toxicities can also have a substantial impact on the quality of life of patients and their families. Patients may be faced with choosing between health care related to their cancer or paying for daily living expenses.[34] Previous research has shown that cancer patients were more likely to file bankruptcy than individuals without a history of cancer, with the risk of bankruptcy two to five times higher among non-elderly patients

given greater variations in employment, income, insurance status, and personal assets.[35] Open dialogue between providers and their patients about these issues could help enable informed decision making that carefully considers both expected benefits and potential high OOP costs of treatments.[35]

Limitations

Although the MEPS is one of the most detailed nationally representative data sources available to estimate OOP burden among cancer survivors and individuals without a cancer history, there are a number of limitations in this study. First, this study relied on household-reported data, which introduces potential reporting biases. For example, the cancer diagnosis question in the MEPS refers to cancer or a malignancy of any kind, which may result in identifying those with pre-invasive disease as cancer survivors. To the extent that this is the case, the impact of cancer survivorship on OOP burden would be underestimated. Second, this study used family pre-tax income rather than post-tax income to compute OOP burden. Although post-tax income may be a more accurate measure of financial resources available to a family, previous research using the MEPS found that OOP burden prevalence was very similar when using pre-tax income, and variations in sociodemographic characteristics were virtually identical.[36] Lastly, the results only apply to the non-institutionalized civilian adult population.

Conclusions

High annual OOP burden is more common among cancer survivors than individuals without a cancer history. High OOP burden has the potential to reduce access to care and the utilization of preventive services. With the continuing increase in the number of cancer survivors and rising healthcare costs, trends in OOP burden among cancer survivors and efforts to improve communication between patients and providers about cost will be important to monitor and follow.

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Table 1.

Characteristics of Nonelderly Cancer Survivors and Individuals Without a History of Cancer: Medical Expenditure Panel Survey, 2008-2012

Characteristics	Cancer survivors, % (95% CI) (*n*=4,271)	Individuals without a history of cancer, % (95% CI) (*n*=96,780)	*p*-value
Time since diagnosis (years)			
0–4	36.7 (34.3–39.1)	–	
5–9	22.4 (20.8–24.2)	–	
10–19	23.8 (21.9–25.8)	–	
≥ 20	15.3 (13.6–17.1)	–	
Missing	1.9 (1.3–2.7)	–	
Age (years)			**<0.001**
18–39	15.1 (13.5–16.9)	48.9 (48.0–49.7)	
40–49	20.0 (18.2–21.8)	21.7 (21.2–22.3)	
50–64	64.9 (62.5–67.3)	29.4 (28.6–30.3)	
Sex			**<0.001**
Men	35.0 (32.7–37.3)	50.1 (49.7–50.5)	
Women	65.0 (62.7–67.3)	49.9 (49.5–50.3)	
Race/ethnicity			**<0.001**
Non-Hispanic white	81.3 (79.2–83.1)	63.9 (62.0–65.8)	
Non-Hispanic black	7.9 (6.7–9.2)	12.3 (11.1–13.7)	
Hispanic	7.3 (6.2–8.6)	16.2 (14.6–18.0)	
Non-Hispanic other	3.6 (2.7–4.8)	7.5 (6.6–8.5)	
Education			**<0.001**
Less than high school graduate	11.7 (10.4–13.2)	15.5 (14.8–16.2)	
High school graduate	27.7 (25.7–29.9)	28.4 (27.6–29.3)	
Some college or more	60.4 (58.0–62.9)	55.7 (54.5–56.8)	
Marital status			**<0.001**
Married	61.5 (58.7–64.3)	52.2 (51.3–53.1)	
Not married	38.5 (35.7–41.3)	47.8 (46.9–48.7)	
Number of comorbidities[a]			**<0.001**
None	24.7 (22.5–27.0)	51.6 (50.9–52.3)	
One	24.8 (22.8–27.0)	23.9 (23.4–24.3)	
Two	21.1 (19.1–23.2)	12.9 (12.5–13.3)	
Three or more	29.4 (27.2–31.7)	11.6 (11.2–12.1)	
Health status			**<0.001**
Excellent/Very good	40.8 (38.5–43.0)	62.3 (61.4–63.1)	
Good	31.1 (29.3–33.0)	27.1 (26.4–27.7)	
Fair/Poor	28.1 (26.2–30.0)	10.7 (10.3–11.1)	
Health insurance			**0.03**
Any private	74.4 (72.3–76.5)	70.5 (69.3–71.7)	
Public only	14.9 (13.3–16.6)	10.6 (10.0–11.3)	

Characteristics	Cancer survivors, % (95% CI) (*n*=4,271)	Individuals without a history of cancer, % (95% CI) (*n*=96,780)	*p*-value
Uninsured	10.7 (9.3–12.2)	18.9 (17.9–19.8)	
Employment status			<**0.001**
Full time	51.3 (48.5–54.1)	61.4 (60.7–62.1)	
Part time	16.5 (14.8–18.2)	18.9 (18.4–19.4)	
Not working	32.2 (30.0–34.6)	19.7 (19.1–20.3)	
Family income			<**0.001**
Poor (<100% FPL)	12.8 (11.6–14.1)	13.1 (12.4–13.8)	
Near poor and low income (100%–200% FPL)	14.6 (13.2–16.1)	16.5 (15.9–17.1)	
Middle and high income (> 200% FPL)	72.5 (70.5–74.4)	70.2 (69.2–71.3)	
OOP healthcare expenditures ($)[b]	2,171 (1,970–2,373)	1,409 (1,360–1,459)	<**0.001**

Note: Boldface indicates statistical significance ($p < 0.05$). Sample sizes are unweighted.

[a]Comorbidities include arthritis, asthma, diabetes, emphysema, heart disease, hypertension, stroke, and high cholesterol.

[b]OOP health care expenditures are in 2012 U.S. dollars.

FPL, federal poverty level; OOP, out-of-pocket.

Table 2.

Prevalence of High OOP Burden[a] Among Nonelderly Cancer Survivors and Individuals Without a History of Cancer: Medical Expenditure Panel Survey, 2008–2012

Characteristics	Cancer survivors, % (95% CI)[b] (*n*=4,271)	Individuals without a history of cancer, % (95% CI)[b] (*n*=96,780)	*p*-value
Total	4.3 (3.5–5.0)	3.4 (3.2–3.6)	**0.009**
Age (years)			
18–39	3.8 (2.3–5.3)	2.8 (2.6–3.0)	0.13
40–49	3.4 (2.1–4.6)	3.2 (2.9–3.6)	0.81
50–64	5.7[c] (4.4–6.9)	4.3 (3.8–4.7)	**0.02**
Sex			
Men	4.1 (2.9–5.3)	2.9 (2.8–3.1)	**0.04**
Women	4.6 (3.8–5.5)	3.8 (3.5–4.0)	**0.04**
Race/ethnicity			
Non-Hispanic white	4.2 (3.3–5.0)	3.4 (3.1–3.6)	**0.046**
Non-Hispanic black	5.3 (3.5–7.1)	4.0 (3.6–4.4)	0.13
Hispanic	4.3 (2.6–5.9)	3.0 (2.7–3.4)	0.11
Non-Hispanic other	3.8 (1.1–6.5)	3.2 (2.6–3.8)	0.60
Family income			
Poor (<100% FPL)	18.4[d] (15.1–21.7)	19.3 (18.2–20.3)	0.63
Near poor and low income (100%–200% FPL)	4.6[d] (3.2–6.1)	3.2 (2.7–3.6)	**0.02**
Middle and high income (> 200% FPL)	1.0 (0.5–1.5)	0.5 (0.4–0.6)	**0.003**
Health insurance			
Any private	3.2 (2.4–4.0)	1.9 (1.7–2.1)	<**0.001**
Public only	7.9 (5.9–9.8)	8.5 (7.8–9.2)	0.55
Uninsured	5.7 (4.1–7.3)	6.1 (5.6–6.6)	0.63
Employment status			
Full time	1.7 (1.1–2.2)	1.1 (1.0–1.2)	**0.02**
Part time	4.2 (2.5–6.0)	3.1 (2.8–3.5)	0.19
Not working	10.2[e] (8.4–12.1)	10.5 (9.8–11.2)	0.77

Note: Boldface indicates statistical significance ($p < 0.05$).

[a]High OOP burden was defined as having annual out-of-pocket expenditures on healthcare services in excess of 20% of annual family income.

[b]Predicted marginals from a logistic regression model controlling for age, sex, race/ethnicity, marital status, education, and number of comorbidities.

[c]High OOP burden was higher among cancer survivors age 50–64 years than among cancer survivors age 18–39 years ($p < 0.05$).

[d]High OOP burden was higher among poor and near poor and low-income cancer survivors than among middle and high-income cancer survivors ($p < 0.05$).

[e]High OOP burden was higher among not working cancer survivors than among cancer survivors working full time and part time ($p < 0.05$).

FPL, federal poverty level; OOP, out-of-pocket.

Table 3.

Access to Care and Preventive Service Utilization Among Nonelderly Cancer Survivors by OOP Burden: Medical Expenditure Panel Survey, 2008–2012

	High[a]		Not high		
	n	% (95% CI)[b]	*n*	% (95% CI)[b]	*p*-value
Access to care					
Has a usual source of care	272	83.3 (77.9–88.6)	3,999	86.7 (85.2–88.1)	0.18
Difficult to get to usual healthcare provider (somewhat or very difficult) among those with usual source of care	272	9.2 (4.8–13.6)	3,999	6.3 (5.3–7.3)	0.15
Unable to get necessary medical care, dental care, or prescription medication	272	19.2 (14.5–24.0)	3,999	12.5 (11.2–13.7)	**0.002**
Delayed any necessary medical care, dental care, or prescription medication	272	21.6 (16.3–26.9)	3,999	13.8 (12.4–15.2)	**0.002**
Preventive services					
Blood pressure checked in last 2 years	272	96.9 (94.3–99.4)	3,999	97.6 (97.0–98.2)	0.52
Cholesterol checked in last 2 years	272	88.2 (83.6–92.7)	3,999	86.0 (84.6–87.4)	0.38
Influenza vaccination in the last year	272	45.1 (37.8–52.3)	3,999	49.2 (47.1–51.3)	0.27
Cancer screening (among age- and gender-eligible individuals without the specific cancer)					
Breast cancer screening (mammogram within 2 years) among women aged > 40 years)	116	63.2 (52.2–74.3)	1,512	75.9 (73.0–78.9)	**0.02**
Cervical cancer screening (Pap test within 3 years) among women aged 21–65 years who have not had cervix removed	91	88.9 (81.9–95.9)	1,386	89.8 (87.6–92.0)	0.80
Colorectal cancer screening (FOBT within 1year, sigmoidoscopy within 5 years, or colonoscopy within 10 years) among adults aged 50–75 years	169	51.1 (42.0–60.1)	2,306	56.1 (53.4–58.9)	0.28

Note: Boldface indicates statistical significance ($p < 0.05$).

[a]High OOP burden was defined as having annual out-of-pocket expenditures on health care services in excess of 20% of annual family income.

[b]Predicted marginals from a logistic regression model controlling for age, sex, race/ethnicity, marital status, education, and number of comorbidities.

FOBT, fecal occult blood test; OOP, out-of-pocket.